

Genetic studies of lung diseases

WHY IS THIS STUDY BEING DONE?

You are being asked to participate in this study because asthma runs in your family. The purpose of this study is to understand how genetics and environment influence the development of lung diseases.

WHAT IS INVOLVED IN THE STUDY?

- ◆ We will ask you to fill out a questionnaire about your lung health and your family's health. (30 min)
- ◆ We will measure your lung function by asking you to blow into a tube. (15 min)
- ◆ The results of the lung function tests will be explained to you (and if you request, sent to your doctor)
- ◆ We will collect 4 tablespoons of blood with a needle and will do genetic studies about lung diseases.
- ◆ We do not plan to provide you with the results of any genetic studies because the results will be preliminary.
- ◆ If the information learned in this study may be important to you or your family's health, we may contact you to see if you would like to participate in a further study in which you will be given the option of learning the results.
- ◆ We will store your blood indefinitely and it will be used by us for future studies about respiratory diseases only.
- ◆ If we decide we would like to do research on other diseases using your blood, we will contact you to ask your permission.
- ◆ Reports from future research done with your blood will not be given to you or your doctor.
- ◆ By agreeing to participate in this study, you do not waive any rights that you may have regarding access to and disclosure of your records. For further information on those rights, please contact Dr. Pi.

WHAT ARE THE RISKS OF THE STUDY?

Blood collection

There may be some physical discomfort when we collect your blood with a needle. There is a small chance that you will develop a bruise, feel lightheaded, faint, or develop an infection at the needle site.

Lung function tests

This may make you feel lightheaded, or may cause you to cough or wheeze. Rarely, some people may need to be given a medicine to breathe in to reverse the wheezing.

Genetic studies

Some people are concerned that research about genetic causes of illness may give information that is not only about themselves, but also about their relatives. Some people are concerned that information about them from their medical records could be released. Possible problems include insurance or employment discrimination. Measures to protect your information are described below. These problems may also occur if you disclose information yourself or agree to have your research records released.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

There may or may not be direct medical benefit to you. We hope that the information learned from this study will benefit other people with lung diseases in the future.

WHAT ARE MY OTHER OPTIONS?

You do not have to participate in this study if you do not want to.

WHAT IF I CHANGE MY MIND?

You may stop participating in this study at any time. If you choose, you may request to have the blood and information collected about you destroyed.

WHO ELSE WILL KNOW THAT I AM IN THIS STUDY?

Data from this study will be identified with a code number instead of your name. The key for this code will be stored in a locked file cabinet. Only Dr Pi will have the code.

If we determine that it would be helpful to enroll other family members in this study, we will only contact them with your assistance and permission.

The blood that we collect from you may be shared with other researchers studying respiratory diseases, along with other information such as your age, gender, and ethnicity. We will share such information, but we will not give other researchers your name, address, or phone number. There will be a code to link your blood with your name and other personal information.

WILL I RECEIVE PAYMENT FOR BEING IN THIS STUDY?

You will receive \$20 for taking part in this study

It is possible that research using your blood may enable researchers to develop medical tests or treatments that have commercial value. You will not receive any money that may result from such commercial tests or treatments.